

An estimated one million people in Scotland are living with a neurological condition which has a significant impact upon their lives. Neurological conditions account for a high proportion of disability, particularly severe and progressive disability, in the population and most neurological conditions affect people's quality of life. It is important that people affected by a neurological condition receive the right care and treatment at the right time.

The Neurological Alliance of Scotland is an umbrella organisation, launched in 2004 to ensure that neurological services are given priority at all levels of health and social care planning.

Alliance members comprise different condition specific charities and not-for-profit groups in Scotland. We work together to support people affected by neurological conditions in Scotland to achieve the best quality of life through influencing policy, raising awareness and promoting the development of services.



Neurological conditions are caused by damage to the nervous system, often as a result of illness or injury. Some have a genetic basis and are inherited. Problems of the nervous system usually affect the brain and spinal cord and the nerves and muscles in the body. Neurological conditions can affect all ages and can begin at any time in a person's life.

The cause of many neurological conditions is not yet known and ongoing research is important to try to understand more about the environmental and genetic factors involved. In general, neurological conditions are not well understood with low levels of awareness even about some of the more common conditions such as epilepsy. As a result of this, people with a neurological condition may face stigma and unhelpful attitudes from others.



## A Manifesto for People Affected by Neurological Conditions in Scotland



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## About the Neurological Alliance of Scotland

The Neurological Alliance of Scotland is a forum of not-for-profit organisations and groups representing those affected by neurological conditions. Our vision is that people living with neurological conditions will have access to the best care possible, have control over their lives and be able to live free from ignorance and injustice.

This manifesto sets out a series of key requests which the Neurological Alliance of Scotland wants the Scottish Government to address in order to improve the lives of those affected by neurological conditions in Scotland.

**“Everyone should have the same access to specialist care but I know that’s not the case in Scotland”**



**“There needs to be more ongoing support”**



### Recognise the impact of neurological conditions on individuals and their families and on Scotland

- Raise public awareness of the impact of neurological conditions on peoples lives
- Develop data systems to collect incidence and prevalence figures of people with all neurological conditions including rarer conditions and ensure data informs service planning and delivery
- Improve support and training for health professionals and all those who assume a caring role through implementation of ‘Caring Together’ – The Carers Strategy for Scotland

### Ensure the voices of people affected by neurological conditions are heard

- Support the Neurological Alliance of Scotland to engage with those affected by neurological conditions via the ‘Neurological Voices’ programme ensuring their influence in the planning, delivery and review of services
- Work in partnership with the Third Sector to engage with people affected by neurological conditions and their carers and families

**“A lot of people think because it’s a brain condition you’re different, but you’re still the same person”**



### Deliver care services that people affected by neurological conditions need

- Ensure that the Clinical standards for Neurological Health Services are fully implemented across NHS Scotland and that clear care pathways are in place irrespective of geographical location
- Continue to support the Managed Service Network for Neurosurgery in Scotland in developing an integrated, consistent, high quality and easily accessible neurosurgical service for the whole of Scotland
- Ensure timely and appropriate social care services are in place, including different types of rehabilitation and access to ongoing care where required and that services work effectively together to support people in living the best life possible
- Recognise the importance of and improve access to specialist clinical services such as speech and language, pain management, neuropsychology and neuropsychiatry services for conditions where there is an expressed need

### Increase knowledge relating to neurological conditions

- Support and increase investment into research into neurological conditions to improve treatment and care of people affected
- Raise awareness and understanding of neurological conditions with health professionals including primary care professionals who are often the first point of contact for individuals

